

# Caregivers and Palliative Care



**GRIEF AND THE WORKPLACE**

**10/13/15**

# Palliative Care



- Palliative care is a multidisciplinary approach to specialized medical care for people with serious and chronic illnesses. It focuses on providing patient with relief from the symptoms, pain, physical stress and mental stress of a serious, chronic illness.

# Place of death



- Journal of Clinical Oncology, July 1, 2015 by Kinoshita et al. *To Better Understand Emotions of Bereaved Caregivers Who Took Care of Patients at Home*
- “One of the most important goals for palliative care is achieving a good death or a good dying process, which is associated with greater family satisfaction.”
- Place of death is recognized as a key component in achieving a good death in patients with terminal-stage cancer. Most patients wanted to die at home, provided they and family have enough support. Attempts to decrease hospitalization at end of life or increase hospice use may enhance patient quality of life (QoL) at end of life and minimize distress in bereaved caregivers. Family members of critically ill patients experience greater psychological distress, including anxiety, depression, posttraumatic stress and prolonged grief, compared with the general population.
- Another study showed lower rates of major depressive disorder (MDD) among bereaved caregivers caring for patients who died in hospice facilities.

# Meaning-Making



- OMEGA – Journal of Death and Dying, April 2013-2014. L.M. Funk et al, *Meaning-Making and Managing Difficult Feelings: Providing Front-Line End-of-Life Care*
- Managing grief and difficult emotions related to end-of-life (EOL) care is an often underrecognized part of the work of resident care aides (RCAs). What ideas do RCAs employ to make sense of death and the provision of EOL care?
- RCAs spoke of personal challenges involved in witnessing death and experiencing loss, as well as helplessness and frustration when they could not provide quality EOL care. Invoking consoling refrains, “they had a full life,” “they are better off,” “such is life”. To manage guilt and moral distress, RCAs reminded themselves “I did my best” and “I experience rewards”. Though some of these ideas helped, RCAs, some staff may benefit from reframing through coaching and mentorship to prevent unintended negative effects.

# Caregiver Burden



- American Journal of Hospice and Palliative Medicine, May 2012. *A Study On Caregiver Burden, Stressors, Challenges, and Possible Solutions.*
- Majority of caregivers reported experiencing role conflict and inadequate stress management.
- Family caregivers stated a need for more support from Hospice agencies, more education on caregiver training, and more public education about Hospice services.
- Faith played positive role in alleviating caregiver burden. (Guide family to social support in their faith traditions)
- **CONCLUSION:** Early identification, intervention, education and coordination of services may help to alleviate caregiver burden, which will improve quality of life for both patient and caregiver.

# Neglected Issue for Social Work



International Social Work, Nov 2009, *Dying old in the 21<sup>st</sup> century: A neglected issue for social work.*

- Older people still have choice and needs about their dying.
- Social workers in all setting should embrace their contribution to quality end-of-life care for older people.

Tools: “Five Wishes”, workbooks to document life, letters to friends and family, etc. Share care plans, know what the doctor recommended, client/customer wants, teams are doing.

# Attachment



- ATTACHMENT is neurobiological and interpersonal.
- We are genetically driven for relational/social closeness. It can feel like a force.
- Know it is there. Know this is a professional relationship. Use the TEAM(S) involved.
- All participating professionals assist the person.
- All participating professionals assist the friends and family, and this helps the person at another level.

# Grief is understanding loss



- Grief = Loss, and making sense of what happened. Model from Elizabeth Kulber-Ross work with terminally ill.
  - Shock
  - Distortion of time (Denial)
  - Anger
  - Bargaining
  - Depression
  - Acceptance.
- No particular order-





- Cycle between and can return to a stage with reminders of the person/loss.
- Actively taking part in processing feelings and memories helps.
- Creating ways to honor, admire and celebrate their loved one helps. We can assist professionally.
- Keeping up with professional literature in fields of death and dying helps.
- Take turns bringing in articles to discuss with team.

# How you think matters



- Cognitive strategies help. Know what this is. Know our job and limitations. Our choice.
- PROACTIVE attitude with practiced strategies = MOST effective.
- Basic distress management – sorting idea  

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Can – DO!	?	Can't do – LET GO!

# Continuum thinking



LEAST

MOST POSSIBLE

☺-----Stress ----- Distress-----Trauma

# Behavioral Strategies



- Behavioral strategies help.
- We are in the human service business/industry. It is OUR JOB to use cognitive and behavioral skills, structure of work and teams, and expand social support in preparation for and during times of stress----distress.
- Boost your healthy behaviors in preparation and during times of distress. =Proactive =Resilient

# Behavioral Skills to buffer



- GOOD and REGULAR SLEEP – review your sleep hygiene and routines
- GOOD and REGULAR EATING – healthy, whole foods – takes planning and organizing
- GOOD and REGULAR EXERCISE – any activity works!
- SOCIAL SUPPORT – expand during times of stress, schedule time with family, friends, plan for asking friends/church to contact you.
- RELAXATION – mindfulness, meditation, prayer
- DO WHAT YOU LOVE. THINK ABOUT WHAT YOU LOVE.

# Be CREATIVE



- Rituals can help. Society has some. We can create more. Honor the person, their life, our life.
- Memorial services, public or private
- Prayer groups
- Funerals
- Do something little, and do it for them.
- Debriefing at work. Can be brief. Anyone can call. E,g, walking meetings, Death Café, Hospice meetings, groups, newsletters.

# Information



- Information helps. Sharing information helps more.
- Journal of Palliative Care, for social science research on ideas form management of chronic conditions.
- OMEGA Journal of Death and Dying
- Journal of Clinical Oncology
- Hospice journals
- Rehabilitation Journals
- Helpful information is AVAILABLE and ONGOING. We live in a time with quick access/technology. USE IT. This is a resource for us in our fields.

# Grief



- Grief can make us feel alone. We have to guard against that and be proactive.
- Grief related to work can remind us of our own grief processing. Know what is yours and have a professional plan and a personal plan.
- Know your job description. Know your choice in your work. Reinforce professional ethics. Standards of practice help set appropriate boundaries. This will lower distress, and shorten duration of distress.



# Self Awareness



- Notice when you feel like you cannot take more or not feeling stable with your usual outlook. Increase social support, plan for more sleep, exercise, healthy/regular food, (beef up behavioral routines), better HYDRATION, multivitamin with minerals and B complex, etc.
- Ok to ask for help from our support systems and periodic therapy services for ourselves when we become overwhelmed. See your doctor if sadness is prolonged. This is what professionals do, recognize own grief issues. We must have better than average skill set for resilience. Ongoing development of these skills helps. It helps to be more informed, practiced and proactive.

# Don't forget being alive



- When you feel surrounded by death, and as if you are taking a hit, don't forget being alive. Grief is about making meaning of loss, the life and relationships of another and our life. Good grief is developing skills and being proactive.
- Distract and redirect. This can be useful.

# Thank yourself



- Appreciate yourself. If no one thanks you, thank yourself. People become distracted in this area. Pat yourself on the back. Reinforce your coping and health.
- THANK YOU for you work, your compassion and your professionalism working with others with chronic conditions, and our helping systems.

# QUESTIONS



## DISCUSSION

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